## AUGUST 7, 2013 MINUTES PATIENT CHOICE AND MEANINGFUL DISCLOSURE WORKGROUP: SPECIALLY PROTECTED INFORMATION SUBGROUP OF THE GOVERNING BOARD OF THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY

The Illinois Health Information Exchange Authority, pursuant to notice duly given, held a meeting of the Specially Protected Information Subgroup of the Patient Choice and Meaningful Disclosure Workgroup at 10:20 am on August 7, 2013, at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with telephone conference call capability.

Participant Name	Participant Representation		
David Carvalho	Illinois Department of Public Health		
Charles (Chuck) Cox	MCHC, MetroChicago HIE		
Mike Jennings	Walgreens		
Marvin Lindsey	Community Behavioral Healthcare Association of Illinois		
Susan Strange	Aetna Better Health		
Dana Crain	Southern Illinois Healthcare		
Mark Heyrman	Mental Health America of Illinois		

Call-in Participant Name	Participant Representation	
Beth Koch	Human Service Center Peoria	

David Carvalho, the Subgroup Chair, called the meeting to order at 10:20 a.m. Introductions of the subgroup members present (in person and by telephone) followed.

## Approval of Minutes

The Subgroup approve the minutes from the July 25, 2013 meeting. With some minor changes from Charles Cox, the minutes were approved by the whole. [The changes have since been made to the previous minutes.]

## Review of Goals

David Carvalho re-read the Action Plan for the Subgroup. David Carvalho mentioned that the recommendations that the subgroup is being asked to make, will be broader than what is covered by the House Bill 1017, which has yet to be signed.

## Defining the Scope of Patient Opt-Out Choice

The Action Plan language calls for the availability of an opt-in choice, but Mark Heyrman described that the group should be discussing an opt-out choice because Illinois has adopted the opt-out. Charles Cox stated that under House Bill 1017, the subgroup is asked to provide the ability to opt-out with meaningful disclosure. The subgroup determined that they will need to come up with a mix of opt-in and opt-out choices given applicable laws.

Charles Cox created a table/chart to clearly lay out the conditions of the current laws and technology.

The subgroup began to discuss the ways in which the table should be filled in [See table 1 for the finished table.] Charles Cox mentioned that HB 1017 is written around a specific opt-out and the categories need to be excluded under the current state of the law. Substance abuse and genetic testing data do not have any clarity on how exchange can occur; currently providers are required to filter those out and not exchange them.

David Carvalho added that non-protected information should be added because participants may still want to opt-out of other types of reporting. The subgroup decided that it was sufficient to create a column as a catchall for specific non-specially protected PHI.

Charles Cox explained that, before HB 1017, provider could only collect specific consent for a specific exchange and maintain that record indefinitely. The consent was only applicable to that one event. David Carvalho stated that the group should assume the bill will be signed.

David Carvalho recommended that the group move forward from specific opt-out to general optout but require an annual state of preference for the availability of specific opt-out when the technology is available. The recommendations should be a compromise of what is available today and what could be feasibly available in the future.

Mark Heyrman stated that everything under general data should also be labeled as HIPAA because everything under that box is subjected to it. He described that HIPAA requires that a specific opt-out is required for anyone paying for their own services. Charles Cox agreed but stated that this should be described under a new column labeled "Self Payer."

Mark Heyrman described that if patients pay for an operation themselves, they should be allowed to segment the procedure out of the records. It is not a total opt-out, it is specific to the chosen record/procedure. Charles Cox argued that this would not be available because the current technology is unable to successfully filter out specific text. The filtering would be over inclusive. With current technology, the filtering would never be 100% successful.

Susan Strange incited conversation about patients with mental health and substance issues and how that would affect their options with opting in or opting out. Are they able to opt in? Will they have no records in the HIE? The subgroup further discussed this topic as well as how these patients with sensitive needs will be approached.

In conclusion of the meeting, all subgroup members agreed that at the next meeting they will pick up where they left off, discussing mental health and substance issues in regard to opting in and out.

Table 1.

	HIPAA (Gen	MHDDCC	HIV		
	Data)	A			
Fed/State	F/ HIPAA	S	S		
General	Current Law	Pre 1017:	Current law, provider can collect and create a persistent		
Opt-out	Yes	No	consent record + share based on that.		
		Post 1017:	Many Providers choose conserv. path and exclude from		
		Yes	HIE exchange.		
Specific	Unnecessary	N/A with	Possible to carve out test results but may be issued with		
Opt-out		current	text reports.		
		tech.			

	Substance Abuse	Genetic Testing	Self Payer	Other (non-specially protected PHI)
Fed/State	F	F	HIPAA	Mix or no Law
General Opt-out	Current law	Current law		Depends on Specific
_	requires provider	requires provider		Data Type.
	to filter out.	to filter out.		
Specific Opt- N/A with current		N/A with current	HIPAA omnibus	Depends on Specific
out	law	law	requires specific	Data Type
			opt-out	